

Patients Who Take Home Their Surgical Pathology Specimens: A Preliminary Study

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Abstract

Patients regularly request to take possession of their human tissues after they have become surgical pathology specimens. To date, few formal research studies have examined the prevalence of this practice or the reasoning patients' request that their specimens be returned to them. This study interviews patients from 2015 to 2017 at one US academic medical center who requested their surgical pathology specimens. Of the 22 eligible patients, 8 patients agreed to be interviewed. Interviews lasted 10 to 30 minutes and included 5 questions. The questions were: (1) What motivated your decision to obtain your surgical pathology specimen, (2) What, if anything, did you do with your specimen, (3) What were positive aspects of your experience, (4) What were negative aspects of your experience, (5) What can the pathology department change to better support patients who request their surgical pathology specimens? Verbatim transcripts were generated and a mixed-methods analysis was performed. The type of specimens included products of conception, placenta and cord, costal cartilage and ribs, loop explant recorder, pacemaker, below knee amputation, and cervix, uterus, Fallopian tubes, and ovaries. The dominant themes included adversity, medical interest, souvenir, cultural beliefs, and curiosity. Subthemes included becoming whole in the afterlife, preservation, my body, restoration, honoring, and regret. In conclusion, pathologists can expand their role as patient advocates and advance patient-centered pathology by supporting patient's individual needs, motivations, and goals, when they request their surgical pathology specimens.

Keywords

surgical pathology, communication, patient-centered, support, patient, products of conception, medical device, amputation

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Introduction

Surgical procedures that remove human tissue become surgical pathology specimens. These specimens are examined by physicians, called pathologists, who specialize in the gross and microscopic examination of these tissues. After examination and diagnosis of a surgical pathology specimen, it is often possible for a patient to request custody of their surgical pathology specimen. Proposed guidelines for this process of receiving, retaining, and releasing surgical pathology specimens to patients have been outlined.^{1,2} Indeed, a document written by the American Perioperative Registered Nurses (AORN) recommends practices that facilitate the possibility of a surgical specimen being returned to the patient.³ Similarly, the Association of Surgical Technologists (AST) in a 2008 policy authored by the AST Board of Directions, *Standards of Practice for*

Handling and Care of Surgical Specimens, suggest processes for returning surgical pathology specimens to patients. The Veterans Health Administration (VA) requires the respective hospital laboratory to have a policy in place for returning surgical pathology specimens to patients, with special attention to accommodating religious needs.⁴ Despite these

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recommendations and mandates, few formal research studies have examined the prevalence of this practice or the reasoning behind patients' request for their specimens. One study of 192 perinatal pathologists across the United States and Canada found that 61% of survey respondents did allow release of placentas, with the most common reason for patient request being to bury the placenta.⁵ One study examined the experience of 47 postoperative patients examining their surgical pathology specimens. This study concluded that patients who saw their specimens gained a greater understanding of their clinical situation and appreciated the experience.⁶ Furthermore, the expansion of patients receiving their surgical pathology specimens could represent a further component of patient-centered pathology.⁷ This preliminary study investigates motivations, values, and needs of those who obtained their surgical pathology specimen at one academic institution in the last 18 months.

Methods

Formal University of Arizona Institutional Review Board approval was obtained (IRB#1702182306). Twenty-two patients signed "Release of Surgically Removed Tissue and/or Prosthesis" forms between May 19, 2015, and January 23, 2017. No protected health information was retained for this study. No patient charts were reviewed. These records indicated patient name, contact information, and type of specimen removed. Patients were called and invited to participate in this study, without compensation. Eight of 22 patients gave consent and were interviewed. Thirteen patients were unable to be contacted due to incorrect or inoperable phone numbers. One patient declined to be interviewed. Interviews lasted 10 to 30 minutes and included 5 questions. The questions were: (1) What motivated your decision to obtain your surgical pathology specimen, (2) What, if anything, did you do with your specimen, (3) What were positive aspects of your experience, (4) What were negative aspects of your experience, (5) What can the Banner University Medical Center Tucson Department of Pathology change to better support patients who request their surgical pathology specimens? Verbatim transcripts of the interviews were generated. Mixed-methods analysis,⁸ a combination of both quantitative and qualitative analysis, was performed on the interview transcripts. An initial review of each transcript was completed by the authors to assign a single word capturing the key theme of each interview. Then, a second review of the interview was performed to generate words or concepts that represented subthemes, with no limit to the number of subthemes that could be assigned. Finally, the frequency of these themes was tabulated.

Results

Age, sex, and type of surgical pathology specimen received by the patient were recorded (Table 1). Additionally, the number of patients in age ranges were as follows: 3 patients between 20 and 29, 3 patients between 40 and 59, and 2 patients over 60 years old.

Table 1. Study Cohort Characteristics.

Age	Sex	Type of Specimen
35	F	Products of conception
36	F	Placenta and cord
25	F	Costal cartilage and ribs
86	M	Loop explant recorder
64	M	Pacemaker
43	F	Products of conception
53	M	Below knee amputation
44	F	Cervix, uterus, bilateral fallopian tube, and ovaries

Abbreviations: F, female; M, male.

Table 2. Dominant Themes.

Dominant Theme	Incidence
Adversity	3
Medical interest	1
Souvenir	1
Cultural belief	2
Curiosity	1

Table 3. Subthemes.

Subtheme	Incidence
Depression	1
Placenta encapsulation	1
Restoration	1
Aid in coping	1
My body	2
Being a medical student	1
Preservation	1
Showing/sharing myself with others	2
Burial	4
Becoming whole in afterlife	2
Prayer	2
Ancestors	1
Honoring	2
Regret	1
Unexpected	1

The single word identifying the main theme, as understood by the authors, is seen in Table 2. Additionally, important subthemes were identified. Themes included: Adversity x 3, medical interest, souvenir, cultural belief x 2, and curiosity. Subthemes included: depression, placenta encapsulation, restoration, aid in coping, my body x 2, being a medical student, preservation, showing/sharing myself with others x 2, burial x 4, becoming whole in the afterlife x 2, prayer x 2, ancestors, honoring x 2, regret, and unexpected (Table 3).

A number of patients provided notable quotations from their experience. On the theme of coping with tragic life circumstance, one patient noted that, "[receiving my placenta] did help ease the experience, as getting the placenta back was more like my original plan [of home birth] that had been disrupted.

Processing why this pregnancy went wrong was very difficult, so it helped with that.” Another patient noted that, “A medical professional called my baby ‘tissue.’ He’s not tissue. I just saw the ultrasound; he was a moving baby in the second trimester. I felt like they were numb to it.”

Two patients expressed how receiving their surgical pathology specimen was an important part of their cultural beliefs. “I am Native American and in our tradition we have a burial for amputated body parts. The burial is in the cemetery, so when we pass on, in the same spot, it will be in my next life.” Another remarked, “[receiving my uterus is important] because it’s part of my body, and I should take everything back, and have everything back, so I don’t have to look for it after my death. This is part, a huge part, of our culture. We say females have a power and the strength that you don’t just throw out.” For one patient, the ability to receive her surgical pathology specimen back was so important that, “I first agreed to do the surgery in 2003 at a local hospital, but they said they couldn’t give me back my uterus, so I did not do the surgery until 2015 when I found a hospital that would allow it.”

To some patients receiving their surgical pathology specimen was about honoring a lost life. “To me the products of conception were my baby. I saw my ultrasound, it was a baby . . . To have him die so suddenly, with no explanation, it was a shocker. It was the most difficult thing I’ve ever gone through. One week he was on the ultrasound everything was OK. Next, he was gone. They didn’t want to do any more tests. I still have no reason for why he died. I have to accept it. But, the burial gave me closure.” Another patient remarked, “You know, we’re not very religious, but we didn’t feel right about disposing her remains as medical waste. So, I carried the pregnancy to term. And then I asked to take home the specimen. Having a burial ceremony wasn’t really about closure but more about the baby girl that we lost . . . We had 2 babies [one intrauterine demise and one viable, born normally] and the dilemma of how to honor both.”

The events that took place at the burial site of each patient’s surgical pathology specimen varied. Many patients chose burial sites of familial significance. “At the burial, me and my children and my boyfriend went to the sacred place to bury him. I buried in the same spot where I lost my brother to SIDS.” Another patient remarked, “The burial ceremony consisted of a few prayers and some silence at the gravesite. We have returned once since we buried him.” Another’s was attended by family and friends, he said, “We dug a hole, 5 feet deep, not quite as deep as if you’re burying a casket. But just like with a person. We covered my amputated leg with cactus pads, so no animals would dig up the gravesite. I was with immediate family and friends. We had a moment of silence, and a prayer or blessing and prayed the rosary. You know, a few prayers for me.”

Emotions at the burial ceremony of a leg were described by one patient and his wife as, “[We were] relieved to get it done with. We were really active, now I [patient’s wife] am the only one that is active. The burial was a way to have it done. Now we are taking it day by day.” The patient commented, “I don’t

know the words or how to explain it. I don’t know how to put it into words. When the burial was happening, I felt good about the fact that someday I am going to be with my leg, as if it never happened.”

To others, receiving their surgical pathology specimen related to medical interest, curiosity, or a sense of ownership over their body parts. One patient said, “I received my pacemaker because I was curious about what I was carrying around in my chest for 7 years. I decided I would show and tell my kids about it someday.” Another patient said, “I got to see surgery and intercostal cartilage in medical school, and this was especially meaningful because I got to see my own cartilage.” For one patient this was about discovery, “I took it home as a souvenir. I talked with and showed it to a friend who had the same thing done to him from Iowa.”

Receiving their surgical pathology specimen was also about showing and sharing with others. One patient remarked, “I also used it as a ‘party piece’ and would show friends when they would come over for a party or get together.”

In the time since receiving their specimens, patients have responded in different ways. One patient noted that “[. . .] people are surprised to see me getting along so well. For example, there is a woman I see at Walgreens who has a husband who this same [amputation] happened to. But he has never been able to walk, he stays in a wheelchair. She told me that seeing me inspired her to go home and tell her husband that he could also be like me. This was very meaningful for me.” The wife of a patient remarked, “Most people on the [Native American] reservation who [undergo leg amputation] want a wheelchair and confine themselves to it. I said, I wouldn’t let my husband use it. Now on our second year, we went to Mount Lemon and he was able to walk in the snow.” After their experience one patient suggested a better system for patients seeking their specimens. “It would be nice to have a dedicated form with a question like ‘would you like your placenta back.’” The patient believes that “many people are asking for their placenta, it would be nice to have it as a part of regular protocol.”

Discussion

The phenomenon of patients requesting and receiving their surgical pathology specimens remains poorly tracked and underreported. Numerous organizations including AORN, AST, private pathology laboratories, and the VA permit the practice and implement policies to that effect.¹⁻⁴ Little research has examined why patients request their specimens be returned to them and what their experience is in this process. This study demonstrates a wide array of motivations. Patients request their specimens because of cultural beliefs and a desire to be made whole again in the afterlife. Some want to honor a lost life. Still others are curious what is inside them and feel a sense of ownership of their body parts. For many patients, their experience helped them cope with tragic life circumstances. In receiving their surgical pathology specimens, patients were better able to process what had occurred and why.

It is tempting to view this work in solely a novelty or medical anthropology perspective. However, the authors believe understanding patients' motivations and experience serve 2 purposes. Firstly, this restores humanity and patient-centered pathology to the forefront of the field. Pathologists can, and should, advocate for their patients by supporting patients who choose to request the return of their surgical pathology specimens. It is evident from this study that patients gain a great deal of psychological, emotional, and spiritual benefit from receiving their specimens. After a 20-minute interview attended by the pathologists, the patient, and his family, the patient remarked, "this meeting did more to help me cope with happened to me than the entire previous 2 years combined." With this understanding, pathologists can practice the sacred healing contained within the art of doctoring.

Secondly, this information can be used for quality improvement. Thoughtful consideration can be given to amending pre-surgery paperwork to include information related to requesting surgical pathology specimens. This will not only make the process easier for the patient, but it will also make their request feel more normal and supported by the medical staff. Indeed, one patient delayed her surgery over 10 years until she found a provider that agreed to facilitate giving her specimen back. As a matter of safety, each institution's department of pathology should thoroughly review procedures in place for patients who request their surgical pathology specimens. Consideration can be given to easing the process and putting in place measures that ensure the patients receive their specimens in a safe manner consistent with their goals. If the patient expresses interest in burying the specimen, consideration can be given to thoroughly rinsing it of formalin before transfer to the patient.

The returning of surgical pathology specimens cannot be without consideration of its impact on the medical evaluation and legal implications of this change in custody. As outlined in previous publications,¹ ample time for the pathologist examination, and subsequent time for the clinical team's additional requests, should be given. Legally, there appears to be 2 main considerations, consent and liability. To obtain adequate consent, each department of pathology should have a process for releasing surgical pathology specimens to the custody of the patient. Prior publications address this consideration¹ and suggest release forms that require attending pathologist signature, patient signature, and a process for informed consent and proper notification of any potential biohazards associated with the specimen. The second consideration is for subsequent liability. While it is possible for a patient to retain custody of their surgical pathology specimen for the purpose of second opinion, as this study shows, this practice appears to be rare. The dominant motivation of patients is to retain their specimen for meaningful personal purposes. Furthermore, while the pathologist and clinical team have a right to examine the specimen and retain it for such purpose, the authors do not believe that the

ultimate ownership of a surgical pathology specimen is that of the hospital. Pathologists are custodians of surgical pathology specimens, not owners. This conceptualization is in line with the encouragement of organizations such as AORN, AST, and the VA.

In conclusion, pathologists can expand their role as patient advocates, and advance patient-centered pathology, by better supporting patients who request their surgical pathology specimens. This support can take many forms, from a brief meeting with the patient to understand and support their needs, to quality improvement changes to hospital forms and processes in specimen handling.


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